



# APS Foundation of America, Inc.

## Frequently Asked Questions

### Frequently Asked Questions about APS Answers to Questions 11-20

*This FAQ is adapted with permission by the [Rare Thrombotic Diseases Consortium](#). Some answers were also provided by members of our [Medical Advisory Committee](#).*

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#### 11. **If you have Lupus, does that mean you also have Antiphospholipid Antibody Syndrome? Does APS turn into Lupus?**

The answer to both questions is no, although the odds of your having one are probably a bit higher than average if you have the other. These are two distinct conditions and, while they frequently overlap, many people have one and not the other. The two major antibodies that distinguish APS, ACL and LAC, are frequently found in [lupus](#) patients, and certain other antibodies also occur with higher-than-normal frequency in both conditions. But the presence of one or more of these antibodies doesn't necessarily mean that you have either condition; the diagnosis for either requires specific clinical evidence, not just antibodies found in lab tests.

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#### 12. **What is an INR and what range should it be kept at?**

A person not on warfarin (=Coumadin®) has a value around 1.0 (usually between 0.7 - 1.3). This is called a "[normal INR](#)". Once a patient is on Coumadin®, the INR increases. The higher the INR, the "thinner" the blood. Patients with DVT or PE are often kept at a [target INR range](#) of 2.0 - 3.0. This is also called "[therapeutic INR range](#)". If the INR is above 3.0 in that patient, the blood is too "thin"; if the INR is below 2.0, the blood is not "thin" enough. If a patient has had a second clot in spite of a therapeutic INR, the physician may increase the target INR range to 2.5 - 3.5 or even to 3.0 - 3.5. If one gets above 3.5, there is usually no increased benefit regarding the protection from blood clots, but the risk of bleeding increases significantly. However some APS specialist recommend an INR of 3-4.5. Some patients who have a [lupus anticoagulant](#) that influences the INR, rendering the INR unreliable. Warfarin (=Coumadin®) therapy in these patients needs to be monitored by a test different to the INR, such as factor II level, chromogenic factor X level, or the P&P test. [Back to top.](#)

#### 13. **Do you recommend a home INR machine?**

This question relates to situations in which patients may be receiving anticoagulant ("blood thinner") therapy; such therapy may be needed in a number of conditions, sometimes including APS, and use of a device to follow the therapy may be required, in the form of an INR monitor. (The initials stand for International Normalized Ratio; the monitor measures clotting time in comparison to the normal range of values, essentially evaluating the effect of the therapy.)

Should such monitoring be undertaken at home? Usually, the answer is no, but that may depend on the individual situation, especially how often monitoring is needed and whether there is some difficulty in the patient's visiting the doctor's office or other facility where the monitoring normally takes place. Cost may also be a factor (the monitors are not inexpensive), as may insurance coverage. Medicare, for instance, will provide compensation only under very specific conditions (see details at <http://www.hgsa.com/newsroom/news05062002.shtml>); other carriers doubtless have coverage criteria, as well. You should discuss the question with your own physician.

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*\*Many people have problems with such machines giving accurate INR readouts. This could potentially be life*

*threatening. Please be aware of these risks when researching & using these machines. Many of these machines have disclaimers about these risk factors, please be sure to read all manufacturer disclaimers prior to using/buying one of these machines.\**

#### **14. How long do I need to take Warfarin?**

Since APS does not go away, you will need to take some sort of anticoagulation for the rest of your life. [Back to top.](#)

#### **15. Can I eat Vitamin K rich foods?**

Yes, but consistency is the key. Some general nutrition dietary guidelines are: 1) Maintain the same diet, eat the same types of foods you ate regularly unless otherwise instructed. 2) Consult your doctor regarding any diet changes. 3) Avoid "binge" and crash diets. 4) Consult your doctor before taking any vitamins, mineral supplements or new medications. 5) An excess of foods high in vitamin K could have an affect on your anticoagulation: Limit to 1 serving per day (1 cup raw or ½ cup cooked): Spinach, Turnip greens, Cucumber peel, Broccoli, Brussels sprouts, Green scallion, Cabbage, Mustard greens. Avoid eating parsley, kale, seaweed, and green tea. [Back to top.](#)

#### **16. What lifestyle changes must be made to accommodate Antiphospholipid Antibody Syndrome?**

For asymptomatic individuals who have antiphospholipid antibodies, some doctors recommend aspirin therapy, but, generally, no major lifestyle changes are necessary. For patients who have the antiphospholipid syndrome and have had a blood clot, treatment consists of anticoagulant therapy ("blood thinners"). Anticoagulant therapy with warfarin (most commonly, Coumadin®) does require attention to one's diet (for a stable intake of vitamin K) and regular blood checks to monitor the medicine. Other recommendations for patients on warfarin therapy would be the same as for any individual who needs to take warfarin. Patients with problems with recurrent miscarriages may need to take a different type of blood thinner (a low molecular weight heparin, such as enoxaparin or dalteparin) during subsequent pregnancies. Lastly, patients with antiphospholipid antibodies should try to minimize any other blood clot risk factors (for example, not smoking, or not taking oral contraceptives or hormone replacement therapy). [Back to top.](#)

#### **17. Why is Antiphospholipid Antibody Syndrome difficult to diagnose?**

In theory, diagnosis is easy. The doctor simply needs to think of the possibility of [Antiphospholipid Antibody Syndrome](#). However, the features can seem so unconnected (e.g. memory loss, previous DVT, headaches, previous miscarriage and 'multiple sclerosis') that the diagnosis may not come to mind. [Back to top.](#)

#### **18. What are the aCL, LA, beta2 glycoprotein1 tests?**

These are the blood tests that are used to diagnose [Antiphospholipid Antibody Syndrome](#). [Back to top.](#)

#### **19. Do all Antiphospholipid Antibody Syndrome patients have the same symptoms?**

By definition, all patients with antiphospholipid syndrome have some type of blood clot, affecting either the arteries or the veins, or recurrent miscarriages or certain other complications during pregnancy. Other problems that may be seen in patients with antiphospholipid syndrome may include a particular type of rash (livido reticularis), low platelet counts ('thrombocytopenia'), heart valve problems, certain fingernail changes, or other signs or symptoms. Lastly, some individuals may have elevated antiphospholipid antibody levels but be completely asymptomatic. In this situation, the antibody may have been detected by blood test results drawn prior to a surgical procedure, or for some other reason. [Back to top.](#)

#### **20. Does taking Aspirin or Warfarin affect the test results?**

It may very well do so, depending on the precise nature of the test(s). When you're scheduled to have any blood testing, talk to the physician ahead of time about any medications (prescription or not) that you take on a regular basis, and follow his or her instructions, which may involve skipping doses, not taking the medication within a certain number of hours prior to the test, etc. Usually, the physician, or someone in the doctor's office, will offer any necessary directions routinely--but if nothing's volunteered, ask, just to be sure. [Back to top.](#)

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Some answers were also provided by members of our Medical Advisory Committee.*

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